Community Assistantship Program

Minnesota Children with Special Health Needs Development and Behavior Clinics Evaluation - II

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Needs (MCSHN) / MN Dept of Health

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Introduction

It has long been recognized that timing is critical for intervening with children who show signs of mental health or behavioral problems. The attention now being paid to school crisis intervention and safety plan issues combined with the knowledge from research that early problems tend to perpetuate each other, shows the need to identify and intervene early (preschool and elementary grades) with children who are showing mental health problems, failing academically, feeling ostracized, angry, and otherwise "not connected." Best practices since at least the mid-80's, have included a growing commitment to a multidisciplinary process.

Children with special health needs are "…those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."[1] The National Survey of Children with Special Health Care Needs found that nearly 13 percent of U.S. children have special health care needs and that 20 percent of U.S. households have a child with special health care needs.[1]

Healthy People 2010 objective 16-23 is to "Increase the proportion of territories and states that have service systems for children with special health care needs." Baseline data reveal that only 15.7 percent of U.S. territories and states had services for children with special health needs in 1997; the *HP 2010* goal is 100 percent.[2] In 1999, the Minnesota legislature mandated progression toward an interagency system to serve children with special health needs aged 3 to 21 years.[3]

Background

Development and Behavior Clinics (DBC) are sponsored by Minnesota Children with Special Health Needs (MCSHN), a unit within the Minnesota Department of Health. DBCs provide a one-day, multi-disciplinary team, diagnostic assessment and discussion meeting (called a "staffing") about the findings. Three children are seen per clinic day. Clinics are held at 10 rural Minnesota sites. There is no cost to the family for this assessment.

Children who are referred usually have multiple issues (behavioral, developmental, educational and/or physical) of concern to the referring party. DBCs focus the efforts of a multi-disciplinary team of specialists on a child's specific problems and stresses, and the team develops a comprehensive plan with the family to prevent further behavioral, emotional, educational and social complications. DBC goals include:

Short-term:

1. Provide access in rural areas to information from multi-disciplinary team assessments for children with complex issues and their families.
2. Make recommendations for follow-up including behavioral and educational strategies, community resources and parent support, and further assessment and/or treatment.

Intermediate:

1. Increase communication between parents and teachers.
2. Rule out other conditions.

3. Decrease parental stress.

Long-term:

1. Better functioning for the child at school, home, and in the community.
2. Better functioning for the family.

The team of specialists varies according to availability at the DBC sites, and generally includes four or five persons. Team specialists include a pediatrician, occupational therapist, speech pathologist, and child psychologist. Two of the DBC teams also include a child psychiatrist, and other teams have a neuropsychologist, behaviorist and/or education specialist.

The DBC intervention provided to families includes a full day of assessment and feedback. Children receive individual assessments in the morning, rotating so they see each of the specialists. Families have an individual afternoon meeting (approximately 45 minutes in length) with the team, school personnel and/or others invited by the family. These staffings are held to discuss with the family the findings of each of the various specialists along with team conclusions, recommendations and strategies.

MCSHN provides the pre-clinic, clinic day facilitation, and post-clinic work. District staff accept the referrals, compile comprehensive history packets (parent and school forms, past testing results, medical and birth records, and psychological records). The chart packets are copied and sent to the team of specialists prior to the clinic. District staff facilitate the clinic day and afternoon staffings. The clinic reports are typed and sent to individuals specified by the parents.

In May 2004, an evaluation of the DBCs was conducted by MCSHN in collaboration with the Maternal and Child Health Program at the University of Minnesota School of Public Health, with funding support from the Center for Urban and Regional Affairs at the University.

The purpose of evaluating the DBCs was to investigate whether or not families perceived a difference in their child or family functioning as a result of attending a DBC; or stated more simply: did evaluation at a DBC make a difference in the lives of these children and their families? Intermediate goals of the evaluation included determining if 1) changes were made in communication between parents and teachers; 2) changes were made in the child's classroom or home to accommodate his/her needs; 3) any other medical/health conditions were "ruled out;" and 4) parental stress decreased.

Evaluation Methods

A family survey was developed by a team of professionals from the Minnesota Department of Health MCSHN program, DBC clinic staff, and staff from the University of Minnesota School of Public Health. Parents of children who attended the DBC clinic were the intended audience of the mailed survey.

The family survey was sent to 286 families in May 2004. Surveys were sent to those families whose child/youth was included in the process evaluation chart reviews and for whom a minimum of one year had passed since the child/youth was seen at a DBC. This one year lag

period gave the family and school time to follow up on the recommendations and allowed for progress to be made by the child/youth. The maximum time from clinic visit to family survey was four years. Of the 286 surveys sent, 114 were returned (39% response rate).

Results

Comparison of Survey Respondents to Survey Non-respondents

Differences between respondents and non-respondents were examined (see Table 1). The majority of families had insurance prior to the DBC referral. While there appears to be a difference in the rate of response among the uninsured when compared with the insured, only 8.8% of the uninsured returned surveys, and this small number precludes any definite conclusions to be drawn.

Table 1: Comparison of Respondents and Non-Respondents

	Respondents (n = 114)	**Non-Respondents** (n = 172)
Insurance status		
Insured	111 (44.0%)	141 (56.0%)
Uninsured	3 (8.8%)	31 (91.2%)
Referral source		
School	61 (35.1%)	113 (64.9%)
Health care provider	27 (42.2%)	37 (57.8%)
Family	12 (60.0%)	8 (40.0%)
Other	12 (42.9%)	16 (57.1%)
Age of child		
0–8 years	79 (36.7%)	136 (63.3%)
9–14+ years	35 (49.3%)	36 (50.7%)
Clinic site		
Willmar	24 (28.2%)	61 (71.8%)
Mankato	32 (45.5%)	39 (54.9%)
Austin	33 (50.0%)	33 (50.0%)
Bemidji	8 (47.1%)	9 (52.9%)
Cass Lake	3 (25.0%)	9 (75.0%)
Park Rapids	5 (45.5%)	6 (54.5%)
St. Cloud	5 (45.5%)	6 (54.5%)
New Ulm	3 (33.3%)	6 (66.7%)
Roseau	1 (33.3%)	2 (66.6%)
Wadena	0	1

Referral sources were compared for respondents and non-respondents. The most common referral source to the DBCs was schools and 35% of those families returned the survey. Health care providers referred approximately 1 out of 5 families, and 42% of those families returned the survey. There were 20 families who referred their own child and 60% of those families returned

the survey. The high response rate among family self-referrals may demonstrate an increased interest and investment from these families.

We examined whether the age of the child made a difference in whether or not the parent returned the survey. Of the 215 children who were 0–8 years, 79 of their families (37%) returned the survey compared to 136 (63%) families who did not. For children between 9–14+ years, half (n = 35) returned the survey and half (n = 36) did not.

Willmar, Mankato and Austin were the three clinic sites where the majority of the children were seen. Their response rates varied from 28% to 50%. The other seven clinic sites saw fewer than 20 children each, making any conclusions about differences in response rates unreliable.

Overall, respondents were relatively similar to non-respondents and no definite conclusions can be drawn about their differences.

Demographic Information about Respondents

Eighty-five percent of respondents were the birth parents of the child referred to the DBC (see Table 2). On average, DBC family households had 2.5 children and 1.9 adults. Nearly all (97%) respondents spoke English in their homes, which is higher than the percentage of homes overall

Table 2. Demographic Information for Survey Respondents

Relationship to DBC child	
Birth parent	85.6%
Adoptive parent	10.8%
Other	3.6%
Household size	
Average number of children	2.5 (range
Average number of adults	1.9 (range
Primary language spoken in home	
English	97%
Insurance	
Annual family income	
< $20,000	
20,000 – 29,000	
30,000 – 39,000	
40,000 – 59,000	
Parents' education	
< High school	
High school	
Vo-tech or some college	
College degree	
Graduate degree	

in Minnesota where English is spoken (91.5%).[5] This may be due to DBC clinics being held in rural Minnesota only and the overall Minnesota percentage includes the diverse areas surrounding Minneapolis/St. Paul.

Most survey respondents (97%) had some type of insurance for their child attending the DBC. The median income for respondents fell between $30,000 and $39,999 per year; 46.5% of annual incomes were $20,000–$39,000 and 20% of incomes were $40,000–$59,000. The median income for the state of Minnesota is $47,111; again this includes the metro area and may be slightly lower when just rural areas are considered.[5]

Parents of children who were referred to the DBC were slightly more educated on average when compared to the state of Minnesota: 94% of respondents were at least a high school graduate compared to 87.9% of Minnesotans.[5] Additionally, 29% of respondents had a bachelor's degree or higher; whereas, 27.4% of Minnesotans have a bachelor's degree or higher.[5] Further breaking down DBC respondents—36% had vo-tech training or some college and 10% had an associate's degree.

Did the DBC Visit Make a Difference for the Children?

The over-arching outcome evaluation question was whether the DBC visit made a difference in the lives of the children/youth. More than three-fourths of the families reported the clinic made a difference in their children's school work (82%); behaviors at school (81%); behaviors at home (79%); and emotional health (77%). Little change was noted in physical health (only 40.5% of parents noted physical health was an initial concern of theirs before the DBC clinic evaluation).

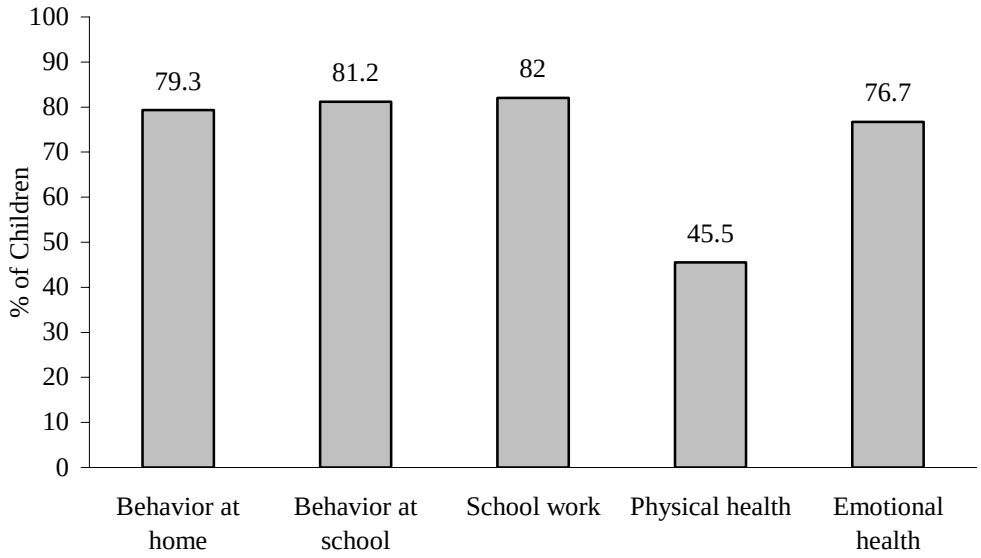

Figure 1. Percent of children who improved in specific areas by following DBC recommendations

Parents also offered the following comments about the value and importance of the DBC for their children and families:

"This is a very good program. Within one year my son was improved from D's to A's and B's in his school work. His attitude at home has also improved very much. I cannot thank you enough."

"This clinic was exactly what our family needed. Our child was able to get SSI for a brief time, which was much needed due to medical evaluation. Also, each person treated us with dignity, respect, and compassion. We are so thankful we had this clinic and didn't have to drive to the cities with our son."

"I am so grateful for your clinic. I don't know what we would have done without the team of specialists. The most convenient part of your clinic is everyone was in one building. The meeting at the end was most informative for me. Once we found out what the problem was, it was like a great burden had been lifted. Thank you so much."

An overwhelming majority (more than 9 in 10 parents) reported they would recommend the clinic to others. This is a positive demonstration that the DBC is making a difference in the lives of families that are attending them.

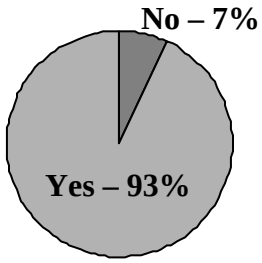

Figure 2. Percent of parents who would recommend the DBC clinic to others

Improvements in Areas of Parent Concerns

Parents were asked what concerns they had before bringing their child to the DBC. The top five concerns included: 1) want to have ways to help my child (87.6%); 2) want to better understand my child's problems (83%); 3) want to better understand my child's needs (78.6%); 4) concerns about my child's anxiety level (75.7%); and 5) concerns about my child's emotional health (75%).

Parents were asked to evaluate whether there were any changes in their child relative to their areas of concern since the DBC clinic visit. In the majority of categories, parents reported improvements (better and much better) in their areas of concern (see Figure 3). This occurred both for parents who had the concern prior to clinic and for parents who did not have the concern before the DBC.

More than 80% of the families indicated improvement in their understanding of their child's needs and problems, in knowing how to help their child, and in their ability to meet their child's needs. More than three-fourths also indicated that the services their child receives at school had improved. More than two-thirds believed their child's work in school had improved, and 62% believed their child's behavior at school had improved.

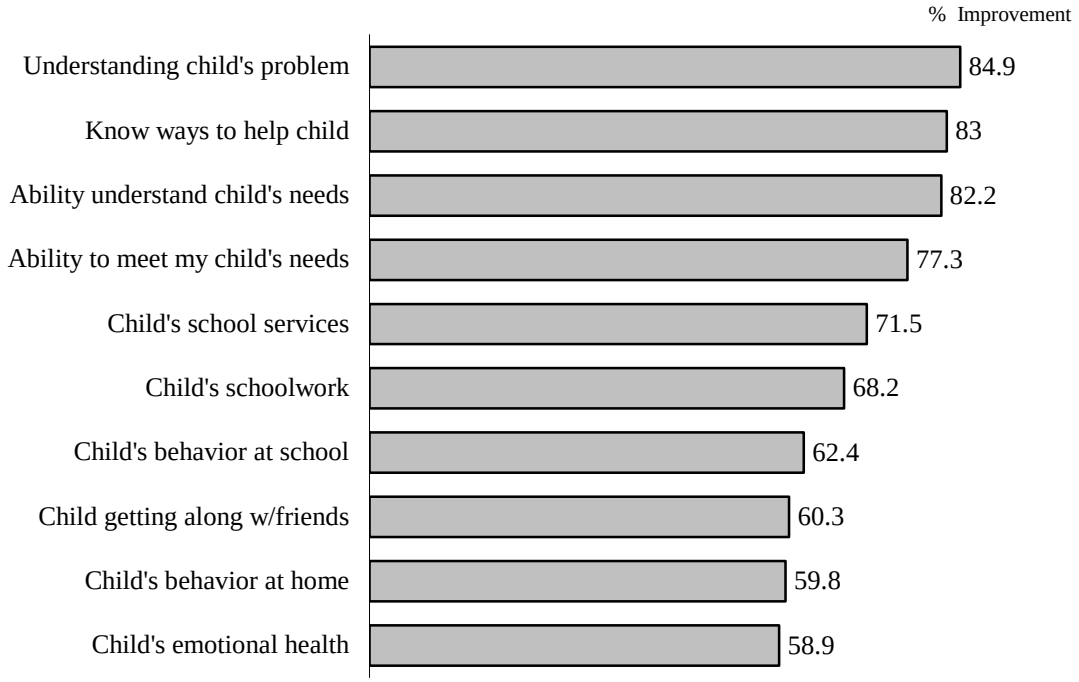

Figure 3. Most frequent areas of improvements since DBC visit

More than half of the families reported several other improvements in their family as a result of the DBC evaluation, including

- Their child's mood
- Family life
- Parent ability to get along with their child
- Communication with their child's teacher
- Child's anxiety level
- How well the child seemed to like himself/herself
- How the child gets along with the parent

After ranking what their concerns were before attending the DBC, parents were asked to reevaluate their concerns based on how things were going at present. Overall, when 21 areas of concern were averaged for all the parents, 61% of parents felt things were better than before the clinic visit. The area of greatest improvement was parents' understanding of their child's problems with 85% of parents indicating they felt their understanding was better than before the DBC. A few concerns remained "about the same," with 67% of parents indicating that their child's physical health had remained the same. This area was also the least likely to be viewed as "better" after the clinic visit, with only 28% of parents stating their child's physical health was better.

Parents' Feelings About DBC Visit

Parents were asked to react to several questions about how they felt during their child's visit to the DBC. For the most part, parents had positive feelings during the visit (see Table 3). Nearly 93% of parents felt the professionals paid attention to what they had to say and about 87% felt that the concerns they had before the clinic visit were addressed. Parents also felt they were

treated as a partner in their child's care (88.1%), and that the staff helped them to better understand their child's needs (80.5%). Additionally, 79.7% of parents felt they learned things about their child, 81.8% learned what they could do to help their child, and 76.7% of parents stated they learned about services in their area to help their child. However, when parents were asked if they learned about school or community services available to help their child only 42.7% agreed they had become aware of these services.

Table 3: Parents Responses to How They Felt During Their Visit to the DBC

	Strongly Agree or Agree %
I felt the professionals paid attention to what I had to say	92.9
I felt like I was treated like a partner in my child's care	88.1
I felt that my concerns were addressed	86.8
I learned what I could do to help my child	81.8
The clinic staff helped me better understand my child's needs	80.5
I learned things about my child I didn't know before	79.7
I learned about the services available to help my child	76.6
I was overwhelmed with recommendations given by the specialists	49.5
I learned of school or community services	42.7
I felt confused about my child's problems	31.8
I felt uncomfortable speaking up	31.3

Parents were also asked whether they felt uncomfortable speaking up while at the DBC, and 68.7% disagreed indicating that they felt comfortable talking while at the clinic. When asked if they felt confused about their child's problems while at the clinic 68.2% of the parents stated they did not. Half of the parents indicated they felt overwhelmed with the recommendations that were given while at the DBC. Given this high percentage, it may be helpful to prioritize recommendations and clarify them with follow-up information sent to families.

Clinic Recommendations and Family Follow Through

During the clinic visit, professionals suggested a variety of strategies to address the child's developmental or behavioral needs. In the survey, parents were asked to indicate if a recommendation was made for their child. If so, they were asked if they were able to follow (or planned to follow) it or if they were not able to follow the recommendation. See Table 4 for results.

More than two-thirds (67.5%) of the families indicated the clinic staff recommended that their children receive occupational, physical or speech therapy or that current therapy services be expanded. This recommendation was followed for 93.5% of the children for whom the recommendation was made. Special education services (either an expansion of current services

or adding special education as a new service) were recommended for 59.6% of the children. This recommendation was followed for 94% of the children.

Table 4: Clinic Recommendations and Parents' Follow Through

Recommendations made for children	n (%)	% who did, or plan to follow	% not able to follow
Add or increase therapy (OT, PT, or speech)	77 (67.5%)	93.5	6.5
Add or increase other education services	68 (59.6%)	94.1	5.9
See medical specialist for further evaluation	66 (57.9%)	83.3	16.7
New medication or change in medication	59 (51.8%)	76.3	23.7
More testing by school	56 (49.1%)	89.3	10.7
Add or increase paraprofessional in school	46 (40.4%)	82.6	17.4
Child or family counseling	46 (40.4%)	76.1	23.9
Apply for MA, MNCare, or TEFRA	45 (39.5%)	82.2	17.8
County case management (DD or CMH)	45 (39.5%)	71.1	28.9
Parent support	41 (40.0%)	56.1	43.9
Apply for SSI	36 (31.6%)	61.1	38.9
Community recreation activities	33 (28.9%)	75.8	24.2
Respite care	30 (26.3%)	46.7	53.3
Mentor	24 (21.1%)	45.8	54.2
Personal Care Attendant	22 (19.3%)	45.5	54.6
Other recommendations	15 (13.2%)	66.7	33.3

Further medical evaluation was recommended for more than half of the children (57.9%) with the recommendation followed for 83.3%. New medications or change in current medications were recommended for more than half of the children (51.8%) with the recommendations followed for 76.3% of the children.

Children were least likely to receive recommended personal care attendant services or a mentor (54.6% and 54.2% respectively). Parents were least likely to receive recommended respite care services (53.3%).

Problems Encountered in Following DBC Recommendations

Families were asked about the types of problems they may have encountered in following through with DBC recommendations. The majority of families reported having no problems with recommendations made at the clinic. As shown in Figure 4, the most common problem families ran into was that services were not available where they lived (27.8%), the services recommended cost too much (26.7%), and the school wouldn't or couldn't do what was recommended (22.4%). The least likely to be problematic for families included: the parent

getting time off from work to follow-up with recommendations (9.3%), having transportation problems (10.2%), and the child not having health insurance (10.3%).

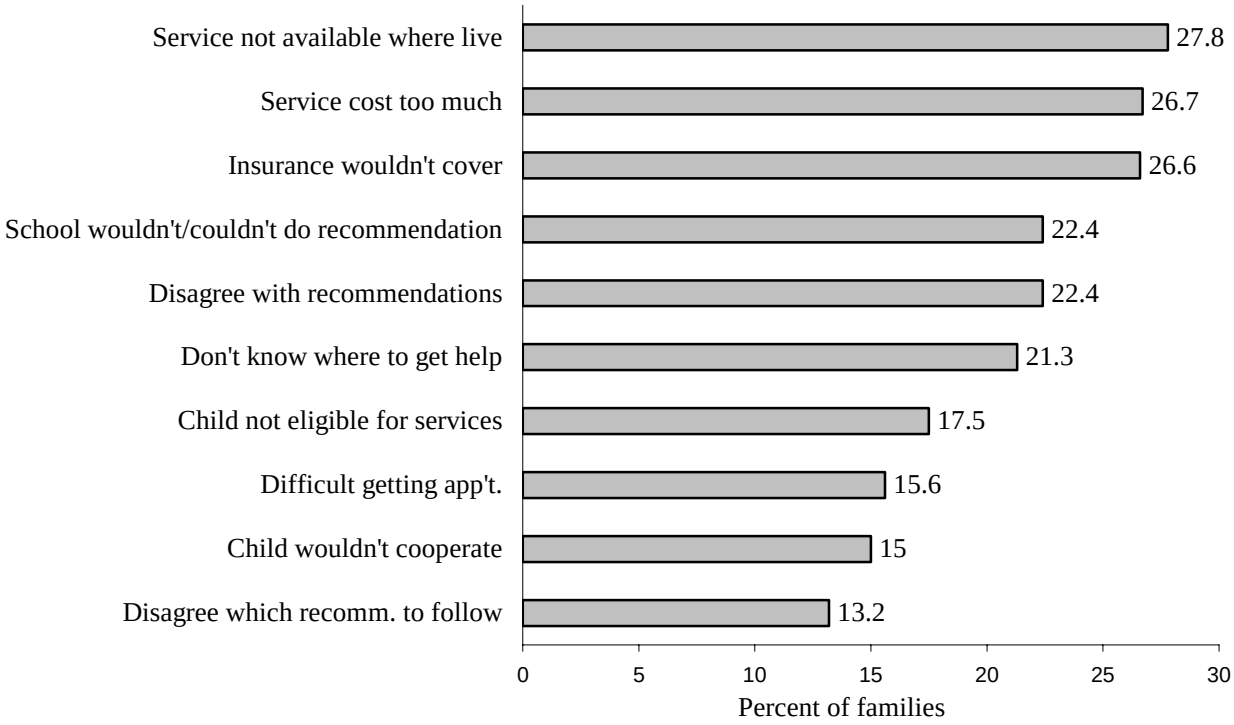

Figure 4. Problems experienced by families in following DBC recommendations

Changes in Family Life Following the DBC Visit

Families were asked if they made any changes in their family life based on the time spent at the clinic, and if yes, whether those changes were still in place. The majority (70.5%) of parents reported making some changes in their family. Additionally, of the families that reported making changes, more than half (60.8 %) had most or all of the changes still in place.

Did you make changes in family life?	n (%)
No	33 (29.5%)
Yes	79 (70.5%)
All changes still in place	13 (16.7%)
Most changes still in place	35 (44.9%)
Some changes still in place	20 (25.6%)
None of changes still in place	3 (3.8%)

Discussion

Overall, the Family Outcome Survey for the DBCs has resoundingly positive findings. Having 93% of families respond that they would recommend the DBC to others may be the strongest affirmation that the DBC was able to provide helpful services to the families involved. The results of the family survey verify that the DBC model is an appropriate and beneficial way for families and professionals to come together and discuss the well-being of an individual child. Continuation of this program has the potential to improve the mental health of children in rural Minnesota by providing mental health assessment to children in less densely populated areas that often are unable to access these services.

Surveying the parents of children attending the DBC appears to be the most effective and beneficial way to follow-up with the result of how families adapted and made changes to their lives and the lives of their children. Although schools are the largest referral source to DBCs, schools will be less likely to know outcomes for any specific child, especially over a longer follow up period. Parents/caregivers are the ones that must follow-through with DBC recommendations, and they also are in the best position to assess the impact of the DBC process on their children.

For this sample of DBC users, it is important to note the large percentage of parents who followed through with recommendations made. This, of course, may largely account for the positive changes observed in their children and the generally positive attitudes parents had about the DBC experience.

Despite the high level of follow-through on recommendations, there were clearly barriers that prevented families from following through on some of the recommendations. Lack of access because of rural location, cost, or lack of insurance were the most frequently cited barriers. In the future, DBCs may want to consider where the services recommended are available to the families and if they will be covered by the insurance the child has. State-level policy recommendations may also help to reduce these barriers.

Although the response rate for a survey of this type was respectable, it is quite probable that families who were more satisfied with the DBCs were willing to take the time to complete and mail back the survey. Hence, the level of satisfaction with the DBCs may be somewhat inflated, and caution should be taken to generalize beyond those who responded.

Conclusions

- The children/youth served by the DBCs are referred for numerous mental health problems and academic issues. A large majority of them meet the screening criteria for more than three DSM-IV disorders, and are already significantly behind in school.

- A large majority of the children/youth seen at the DBC are enrolled in rural, very small school districts. Schools make the majority of the referrals to the DBC.

- Families are able to implement the majority of the recommendations made for their child and family

- Families overwhelming would recommend the DBC to other families/caregivers.

- The DBC model is effective. Families spent a short amount of time at the clinic (½ day of assessment and a 45 minute staffing), yet families report the DBC made a difference in the life of their child, showing improvement in numerous child outcome indicators.